

BUILDING YOUR HEALTHCARE TEAM

When you're receiving the whole-body care needed to live better with Parkinson's, your healthcare team could consist of more than ten different professions. And when you're working with the right professionals, your ability to manage your Parkinson's improves greatly.

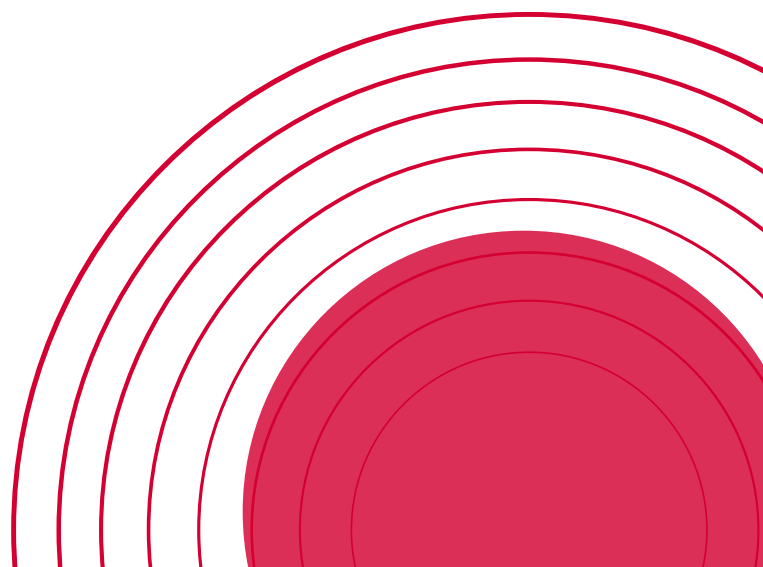
Here are 13 professionals to consider reaching out to, as well as questions and considerations to aid in your decision-making before moving ahead with a service.

Many of the questions below can be asked of most, if not all, of the professionals. You can explore the question lists and apply them to your conversations with any of the following healthcare services. Understanding what is available through public funding and which are considered private services will help you budget and prioritize the services most important to you at the time. What is covered by provincial healthcare will differ from province to province, so it's essential to make the question of public services versus private services a part of every conversation with your healthcare team.



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FAMILY PHYSICIAN

Your primary care provider or family physician, also called a general practitioner (GP), is the person you will likely see most often. This is the expert you will go to first when you are not feeling well. After assessing your signs and symptoms, your doctor may provide you with a prescription, recommend treatments, make referrals to specialists and order tests for specific purposes. You can also ask questions of your family doctor to learn about your Parkinson's and other health issues you may be experiencing.

What to ask your Family Physician

- What other specialists can help manage my Parkinson's?
- Do you communicate with them?
- Would it be helpful if I report to you the outcomes and information I gather from my appointments with my specialists and other healthcare professionals (i.e., occupational therapist)?
- In addition to getting treatment from other specialists, what other support do you recommend?
- Where can I find local wellness programs and support?

NEUROLOGIST

A neurologist is a specialist who has completed a three-year training program in the field of neurology in an accredited training program. Your neurologist is likely the one who will have diagnosed you with Parkinson's. A neurologist will assess what symptoms you are experiencing, to what degree you are experiencing them, and what medications you need to manage them. You will not likely see your neurologist very often, but they will be the one who decides on the need for changes to your medications or other treatment needs.

What to ask a Neurologist

- What percentage of your patients within your practice have Parkinson's?
- What symptoms of Parkinson's should I be on the lookout for?
- Do you belong to an association or group of neurologists that you can discuss your Parkinson's cases with for more opinions?
- What can I expect during our appointments together?
- What should I do if I have questions or concerns about my Parkinson's between appointments?
- When should I seek out a Movement Disorders Specialist?
- Should I get a second opinion?

MOVEMENT DISORDER SPECIALIST (MDS)

An MDS is a neurologist or neurosurgeon that has completed a fellowship in the field of movement disorders who has additional specialized training in Parkinson's and atypical parkinsonisms. You may be referred to an MDS by your family physician or neurologist if they, or you, feel more specialized care is in your best interest.

What to ask an MDS

- How do you tailor treatments specifically to a patient when Parkinson's affects everyone uniquely?
- What does a typical MDS appointment consist of?
- What should I do if I have questions or concerns about my Parkinson's between appointments?
- Should I continue seeing both an MDS and a neurologist?
- I have another health condition. How does that impact my Parkinson's and the care you provide? How can I make sure my full spectrum of health needs is being considered and managed?
- Do you belong to an association or group of Movement Disorder Specialists that you can discuss your cases with for more opinions?

PHARMACIST

A pharmacist will dispense medications based on prescriptions received from physicians. In some provinces, pharmacists are also permitted to prescribe medications to individuals. Your pharmacist is the person who can best counsel you on the use of your prescription and over-the-counter medications. They can advise you of medication side effects as well as any reasons you may not be a candidate for a certain medication. They can also provide you with information on nutritional supplements. For that reason, it is recommended that you stay with one pharmacist to ensure they're able to advise you if one medication is incompatible with another.

Questions to ask a Pharmacist

- What medications do you see prescribed to people with Parkinson's?
- Do you have any concerns about side effects or my compatibility for [x] medication?
- Is there a specific way I should be taking [x] medication (i.e., time of day, with or without food/drink, other)?
- What are the common concerns people living with Parkinson's bring to you regarding their medications?
- How do you help people navigate challenges with medication?
- How long have you been in business/working as a pharmacist here?
- Do you offer compounding services in the event I cannot swallow my pills?
- Do you offer customized blister packs to help me avoid confusion about medication timing and dosing?
- Do you offer free one-on-one consultations to review all of my medications with me?

CLINICAL NURSE

This healthcare provider is a registered nurse who specializes in Parkinson's disease and other parkinsonisms. You will likely see them more frequently than your neurologist. Sometimes the clinical nurse works in a neurologist's or movement disorder specialist's clinic. They monitor Parkinson's patients to ensure their medications are working, assess side effects and their impact, provide support, and are a source of information on the disease and the therapies that may improve quality of life for you.

Questions to ask a Clinical Nurse

- What strategies have you seen be most helpful for someone with Parkinson's like mine?
- How do I teach my other health care providers about my Parkinson's?
- When are you available? How do I access support more immediately when I need it?
- How many appointments may I book with you at one time?
- Will you work with my care partner, too?

PHYSIOTHERAPIST (PT)

If you are addressing all of your needs, then you are likely to see a physiotherapist, also called a PT. Through targeted exercises, this health provider will help you to build strength and better control the movement of your muscles. They may be trained in delivering a type of therapy called the Lee Silverman Voice Treatment (or LSVT). PTs will also work with you to gain more flexibility and improve walking and balance to prevent falls and help with freezing episodes. A physiotherapist will also train you to do exercises at home that will help to maintain your mobility so you can continue to do many of the things you did before.

When located in a hospital, the costs of physiotherapy are covered by your provincial health plan. Outpatient or community physiotherapy services may be covered by extended health plans.

What to ask a Physiotherapist

- Do you have experience working with people with Parkinson's or other neurological disorders?
- Are you LSVT BIG certified?
- Is a doctor's referral required to be treated by a physiotherapist?
- How long are physio appointments, and how is my progress measured?
- When will I begin to feel relief from my pain?
- How do you stay current on the latest developments in Parkinson's physio care?
- Is physio done in person or are there virtual options?
- What type of equipment will I be provided or will I need to purchase to do prescribed exercises at home?

OCCUPATIONAL THERAPIST (OT)

The focus of an occupational therapist - also called an OT - are the activities of daily living such as eating, sleeping, bathing, dressing, toileting, as well as work and leisure activities. They will assist you by strategizing on how best to manage these activities while remaining safe and reducing the risks of injury. An occupational therapist can also recommend appropriate devices and technology to support any other needs identified. If funding for any device is a challenge, they will be able to guide you to the right support network and information.

What to ask an Occupational Therapist

- Do you have experience working with people with Parkinson's or other neurological disorders?
- How do OT's create customized care plans for people with Parkinson's?
- How is occupational therapy different from physiotherapy?
- How does occupational therapy help me keep my independence?
- At what point in my Parkinson's progression should I be working with an OT?

PERSONAL SUPPORT WORKER (PSW)

A personal support worker, or PSW, is a healthcare provider that is found in both private and public healthcare facilities. From assisted living housing to personal homecare visits, PSWs are qualified to lend a hand in numerous ways. They have knowledge of medication administration, documentation, nutrition, and supporting people with mobility disorders by helping them perform the physical and occupational therapy strategies prescribed by PTs and OTs. The first step to receiving in-home care from a PSW is contacting your regional health authority to be assessed for eligibility under your province's healthcare system. Once assessed, you can determine if you wish to explore additional services provided by private homecare support services.

Questions to ask a PSW

- Do you have experience working with people with Parkinson's or other neurological disorders?
- Do you receive any Parkinson's specific training?
- Are you publicly funded or do your clients pay you as a private service?
- How do services differ from assisted living/retirement communities compared to in-home services?
- Do I need a doctor's referral to work with a PSW?
- What else do you do for clients?

SPEECH LANGUAGE PATHOLOGIST (SLP)

A speech-language pathologist addresses your needs as they relate to your speech and swallowing. It's best to retain the services of a speech language pathologist immediately after noticing any issues with your voice. They may be trained in delivering a type of therapy called the Lee Silverman Voice Treatment (or LSVT) to improve volume, quality and intonation of your voice. This training also strengthens your breathing, works out your voice box (larynx) and improves your articulation of words. A speech language pathologist will also evaluate your control and ability to swallow. If there are problems with swallowing, known as dysphagia, they can address this through a change in diet and consistency of foods and/or exercises in altered swallowing techniques.

What to ask an SLP

- Do you have any additional training in the field of Parkinson's?
- Are you trained in LSVT LOUD techniques?
- Do you prefer to see your clients in-person or do you offer virtual sessions as well?
- What results can I expect from working with a speech language pathologist?
- How much of your caseload is people with Parkinson's?
- What is your process for developing a personalized plan for me?

MASSAGE THERAPISTS

Massage therapy can provide short-term relief from muscle stiffness and rigidity, help improve blood flow, relieve stress and depression, as well as improve constipation, sleep issues and general fatigue.

Registered massage therapists are based in private practices rather than hospitals and are not covered by provincial plans. Some extended benefit plans provide coverage for massage services. There are numerous kinds of massage, all with their own benefits. Talk to several massage therapists to understand what massage therapy techniques are in their wheelhouse.

Questions to ask a Registered Massage Therapist

- Do you work with people who have movement disorders?
- How does massage help me manage my Parkinson's?
- What length or type of massage do you recommend for someone with Parkinson's?
- I have difficulties with getting up and down, and some days are worse than others. Are you able to accommodate my mobility?
- How often should I get a massage to see the benefits?
- How do you stay current on massage therapy techniques to treat conditions like Parkinson's?
- Do you offer mobile massage therapy, where you provide in-home services?

NUTRITIONAL SERVICES

When it comes to your diet, the best person to work with you is a dietitian. They can help with food selection and meal planning to ensure the food you eat supports your medication absorption. They will also look at your present diet and make changes to it based on your needs and your disease progression. If you are experiencing swallowing problems (dysphagia) or constipation – which is one of the most common symptoms with Parkinson's – then that, too, will be addressed. A dietitian will also consider any vitamin deficiencies, supplementation needs, and protein-related issues with medications.

Questions to ask a Dietitian

- Are you publicly funded or do your clients pay you as a private service? How can I determine if your services are covered under my private insurance?
- What is the difference between a nutritionist and a dietitian?
- Why does my diet matter in Parkinson's?
- Is there an ideal diet for someone living with Parkinson's?
- How do you help me identify my ideal diet?
- Can you help me with dietary planning related to protein interactions with medications?
- How often do people see their dietitians?

SOCIAL WORKERS (SW)

When you live with Parkinson's disease, so does your family. A social worker is someone who can counsel all of you. They will connect you with community organizations and resources to meet your growing and changing needs through all phases of the disease. They will determine which healthcare providers you may still need to see and can help you secure the referrals you need. A social worker will help you plan for your future needs and health-related wishes, as well. They are privy to financial aid and social assistance information, and may discuss home care services, housing options, assisted living, long-term care facilities and respite services with you and your care partner. A social worker will also provide support in times of crisis, and counseling for children with a parent or grandparent who has Parkinson's.

Questions to ask a Social Worker

- Are you publicly funded or do your clients pay you as a private service? How can I determine if your services are covered under my private insurance?
- What other healthcare providers should I consider working with in my area?
- What Parkinson's specific knowledge or skills have you developed that help you work with someone living with Parkinson's and their family?
- Do you visit our home?
- How can I encourage my care partner to attend a support group or talk with you one-on-one?

PSYCHOLOGIST

Trained to help you cope with the emotional impact of a chronic illness and other issues, psychologists employ techniques including psychotherapy and behaviour modification therapies, among others. Some specialize in sophisticated testing of cognitive problems. Some are associated with hospitals and clinics where their services are paid for by provincial plans; in private practices, cost may be covered by extended benefit insurance plans. You can work with a psychologist without a referral from your family doctor. Having trouble finding a psychologist with relevant experience? Ask other people impacted by Parkinson's for recommendations of therapists they know of.

What to ask a Psychologist

- Do you accept insurance or are you able to provide services on a sliding scale (cost based on income)?
- Can you offer in-person and virtual appointments?
- Do you often work with people living with Parkinson's?
- How will working with a psychologist help me?

PSYCHIATRIST

This specialist will diagnose and treat issues related to depression, anxiety, and disturbances in feelings, thoughts, behaviour and cognitive processes that can develop in Parkinson's. Treatments include psychotherapy, marital/family counseling and medication. A unique function of a psychiatrist versus a psychologist, in the context of Parkinson's, is their understanding of appropriate meds for mood or psychiatric symptoms, and how to avoid medications that are not well suited to take alongside Parkinson's meds. You will require a referral from your family doctor or your neurologist to access the help of a psychiatrist. Having a good connection with your psychiatrist is important, so be sure to see someone you feel comfortable sharing with.

What to ask a Psychiatrist

- What mood changes can I expect in Parkinson's?
- How, specifically, will you help with mood changes?
- Why is it important for me to see someone about my mood?
- What type of side effects might I get from medications you prescribe for mood changes? How will these medications interact with the medications treating my motor-symptoms?
- How often will I see you?

PARKINSON CANADA'S INFORMATION AND REFERRAL TEAM

The Information and Referral Team can be your touchpoint for locating support and resources in your local area as well as providing non-medical advice to your questions about Parkinson's. The team operates a toll-free helpline, a service for people living with Parkinson's, their care partners and health care professionals that is available by phone or email. When you have questions or need assistance, our Information and Referral staff help connect you with resources and community programs and services.

You can reach the Information and Referral team Monday to Friday, 9:00 a.m. - 5:00 p.m. ET at 1 (800) 565-3000 or by emailing information.referral@parkinson.ca.

From finding care partner support groups to recommending informative webinars to attend, and everything in between, Parkinson Canada's Information and Referral team is an extension of your healthcare team.

What to ask our Information and Referral team

- How do I meet others living with Parkinson's?
- I'm newly diagnosed. Where do I find trustworthy information about Parkinson's?
- My parent is caring for my other parent with Parkinson's. How do I find help for them?
- What can I do to manage [X] symptom?